Protecting and Promoting Privacy in an Uncertain World

European Journal of Health Law **7**: 185-191, 2000.

NEWS AND VIEWS

Protecting and Promoting Privacy in an Uncertain World: Further Defences of Ignorance and the Right Not to Know

GRAEME T. LAURIE
Faculty of Law, University of Edinburgh, Scotland

Introduction

I welcome the opportunity to respond to the article by Dr Canellopoulou Bottis which discusses my work 'In Defence of Ignorance: Genetic Information and the Right Not to Know'[1], and I would like to extend my thanks to her and to the European Journal of Health Law for giving me cause to reflect once more on my arguments concerning genetic privacy and the right not to know.

Ethics and Law

Let us begin with a point of agreement. Dr Canellopoulou Bottis argues that the answer to my hypothetical example '...cannot, should not be found in law, at least not only...'. I find it easy to agree with this statement. Indeed, as a medical lawyer I baulk at the idea of medical law which is not informed by ethics and ethical discourse and which does not reflect the fundamental values and principles of our society. A theme of my paper was, in fact, to stress the need to have proper reflection and discussion about the appropriate legal responses which should emerge in light of the problems thrown up by advances in genetics. In that process ethics has a crucial role to play. By corollary, I am more than willing to admit that the law does not necessarily have a role to play on every occasion.

This having been said, Dr Canellopoulou Bottis focuses much of her paper on the legal concept of duty (to disclose) and cites a number of legal cases in support of her argument. It is fitting, therefore, to discuss the possible nature of any duty to family members in respect of genetic information, especially

since I disagree with my colleague's analysis in several respects. This is so even although I do not argue in my previous work that any duty to disclose should be imposed on health care professionals.

Law: A Duty to Disclose?

Dr Canellopoulou Bottis raises a question over the 'uniqueness' of genetic information and using that uniqueness as a basis for establishing a duty to disclose: 'the obligation to disclose does not depend on the nature of the information, be it genetic or not'. We are talking here about the action of negligence and the existence of a duty of care. Common law courts use the duty of care as a 'threshold device'[2] to establish the limits of liability; only when a duty of care is imposed can liability ultimately flow in respect of careless action or inaction. In the tripartite relationship under discussion, where the question to be determined is whether the health care professional (A) owes a duty of care to the patient's sister (C), Dr Canellopoulou Bottis relies heavily on the U.S. Tarasoff decision[3] in which the University of California was held liable for the failure of one of its therapists to protect a young woman from one of his patients who had voiced thoughts about murdering her. While it might be tempting to see our genetics scenario in terms of the dynamic in Tarasoff, it is utterly erroneous to do so in law. For, the primary reason why a duty of care was imposed in Tarasoff was because of the unique relationship which existed between the therapist and his patient. In particular, the ability of the therapist actually to control his patient's conduct – for example, by having him committed – was instrumental in the Supreme Court of California finding that a duty of care was owed to a third party outside of the therapeutic relationship. Moreover, the duty which was imposed was not a duty to warn but rather a duty to protect the third party from the conduct of the patient[4]. Thus, the authority in Tarasoff cannot be used in respect of the HIV example offered, nor indeed in respect of genetic information, for in neither case is the health care professional in a position to control the conduct of his patients. And, in the context of genetic information the analogy is removed one stage further because in no way can the conduct of one relative cause genetic harm to any other living relative. The harm, if it is to be seen as genetic disease, has already been done. At best then, a health care professional can only prevent a relative from losing a chance of therapy or survival if disclosure is made in circumstances when therapy or a cure are available[5]. The hurdle remains, however, one of imposing a prima facie duty of care on a health care professional to the genetic relatives of his patients.

In certain U.S. states the courts have cleared this hurdle and have

concentrated on the unique familial nature of genetic information to impose a duty to disclose on health care professionals (HCPs). Thus, in Schroeder v Perkel[6] the court said, "[t]he foreseeability of injury to members of a family other than one immediately injured by the wrongdoing of another must be viewed in light of the legal relationships among family members. A family is woven of the fibers of life; if one strand is damaged, the whole structure may suffer. The filaments of family life, although individually spun, create a web of interconnected legal interests'. And more recently, the Superior Court of New Jersey held in Safer v Estate of Pack[7] that a direct duty existed between a health care professional and the children of a patient who was suffering from retroperitoneal cancer with multiple polyposis of the colon to warn the children of the immediate risk to their own health: '[a]lthough an overly broad and general application of the physician's duty to warn might lead to confusion, conflict or unfairness in many types of circumstances, we are confident that the duty to warn of avertible risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of justice'[8]. The relevance of the nature of the information was key to the foundation of the duty. The strongly hereditary influence of multiple polyposis alerted the health care professional to a specific and easily identifiable class of persons who were at increased risk. Moreover, that class of persons was restricted (being blood relatives of the patient) and so to allow the action did not raise the prospect of opening liability to an unlimited group of potential litigants. Thus the nature of the information founds the duty and determines its scope.

This having been said, it is important to realise that policy factors operate to constrain the courts in their extensions of civil liability. Importantly, social, economic, moral and ethical factors are taken into account whenever an extension of the law is proposed. Thus we see, for example, in Ellis v Peter[9] the Supreme Court of New York refused to recognise a duty on the part of a health care professional to the spouse of a patient who had contracted tuberculosis (but who had been wrongly diagnosed) because 'a physician's duty of care is ordinarily one owed to his or her patient and does not extend to the community at large; the wife may also be considered to be in that class of persons whom the defendant knew or reasonably should have known were relying on him for a duty of care to his patient, but defendant's duty of care will not be so extended, since there is no indication of the point where that duty would end.'[10] The limits of liability in such cases are decided primarily by reference to policy. In the context of genetic information, several considerations should be immediately apparent. These include the burden which a duty would place on HCPs, the difficulty in knowing who should be contacted and how[11], and the possible detrimental effect which such a duty

would have on the physician-patient relationship if confidentiality could be disregarded in favour of the duty to disclose[12]. But, of most importance in the present context, the courts should not rely unquestioningly on an assumption that non-disclosure is necessarily a (legal) 'harm'. As I argued in my original work, the interest in not knowing can be very important, and it will not be served by imposing a duty on health care professionals to make disclosures without first considering the consequences, for both the patient and the relatives to whom disclosure will be made. My conclusion is, therefore, that one way to recognise and protect the interest in not knowing would be to refuse to endorse the extension of tort law to impose a duty to disclose[13].

Ethics: Questioning Existing Principles and Exploring New Options

The ethical basis for my argument in support of a "right" not to know attempts to expose the limits of the concepts of autonomy and confidentiality in recognising and protecting the full range of interests which are at stake when we ask the question, how should we regulate control of, and access to, familial genetic information? The fundamental ethical principle of respect for persons is undeniably a key to resolving these issues from an ethical perspective, but I do not believe that the manifestation of that respect in rigid adherence to the concept of individual autonomy is the only, or indeed the most appropriate, means to address the problems under scrutiny. Dr Canellopoulou Bottis correctly identifies 'choice' as central to the exercise of autonomy, and she sees the right of patients to exercise choice as something akin to a trump ethical value in the resolution of our dilemma. But, of course, the principle of respect for persons requires only that we respect a person's choices once they are made and/or that we do not interfere in the decision-making process once it is embarked upon. The objection which is voiced to my thesis is that it serves to deprive persons of choice, and as such is paternalistic and unjustifiable. But my concern is this: how should we act when we do not know what people will choose? Certainly, one way to respect persons is to respect any choices they might make about their health care when they themselves have sought out the expertise of an HCP, but when they have not approached such a person, and when we have no indication of the choices which they might make about their future health care – which might well include a choice not to know – I do not see how it is respectful effectively to coerce someone into a position of having to make a choice, for example, by taking a genetic test, or undergoing a double mastectomy, or by having a termination of pregnancy. Dr Canellopoulou Bottis is concerned with *facilitating* choices

and her justifications lie just as much in paternalistic practices as do any justifications to respect an interest in not knowing. Let us not be unclear about this.

I full endorse any argument which supports protection for patient choices. But in our scenario no choices have been made. Our dilemma, therefore, is one of whether we should disclose information in order to facilitate certain choices when we do not know if they will be made at all, or whether we should respect an interest which patients might have in not knowing information about themselves. At no point have I argued that a "right not to know" is more important that autonomy and choice, as Dr Canellopoulou Bottis suggests. Rather, my concern is that we should be aware of the possible existence of an interest in not knowing information, and that in certain cases we should respect that interest and not disclose genetic information. An autonomy analysis is flawed in this regard because it does not permit us to respect the person's state of no(n)-knowledge. Autonomy requires choice and choice requires information through disclosure. In seeking to further autonomy the interest in not knowing is thereby automatically thwarted.

The concept of confidentiality is similarly ill-suited to assist in the resolution of our dilemma. And, with due respect, Dr Canellopoulou Bottis misunderstands my point in this regard. I wish to explore the extent to which confidentiality can protect the interest in not knowing; her submissions relate to the extent to which the limits of the duty of confidentiality can justify disclosure to family members. I whole-heartedly agree that disclosures can be justified – indeed, this is precisely my concern – and my conclusion is that the concept of confidentiality itself cannot protect those to whom disclosure will be made from the burden of such knowledge. This having been said, the duty of confidentiality does not impose on HCPs a duty to disclose[14] as seems to be suggested. Rather, and at best, an HCP is accorded a discretion to disclose. None the less, I would submit that recognition of the interest in not knowing should serve to temper the exercise of such a discretion.

These conclusions leave us with a conceptual void in terms of how we can make sense of the full range of interests which are at stake, and in particular of the interest in not knowing. My concept of spatial privacy represents one way of filling that void. I do not consider, however, that this view of privacy has any more value than other ethical principles. I argue only that it should be given due recognition and should be invoked in appropriate circumstances to be weighed in the balance of all ethical considerations. The question of whether we should ever develop a legal 'right' not to know requires much more debate. The concept of 'right' which I envision is one in the realm of negative rights. A spatial privacy right would be one which would entitle the right holder to respect for their state of separateness from others. It is a right

of non-interference. Thus, it is not accurate to suggest, as Dr. Canellopoulou Bottis does, that in our scenario it is the HCP who 'exercises' the right on behalf of the relatives. Rather, he would 'respect' their right and their interest in not knowing by not disclosing the genetic information, in much the same way we respect individuals' liberty interests by not watching them clandestinely. The effectiveness of a legal right not to know would be relevant if the right were infringed, at which point those who are the subject of the right could seek a remedy. It would also be meaningful to talk of the right not to know when the right holders are aware that there is something to know but they would rather not know it. Here there is a choice not to know – arguably an exercise of autonomy which protects privacy interests – and this form of privacy right is the focus of the European Convention and the UNESCO Declaration. Dr Canellopoulou Bottis is entirely correct to point out that these instruments focus on the autonomy of individuals, but I would not argue that autonomy and privacy are necessarily mutually exclusive. I offer the example of these legal documents to demonstrate that the interest in not knowing has already been recognised at the international level, at least in part. However, it is important to realise that these instruments only protect privacy interests to the extent that autonomy and privacy overlap. The overriding concern of my paper was to show that autonomy cannot fully protect all privacy interests at stake, and it should not be expected to do so. In the absence of a means to exercise choice meaningfully while not interfering unduly with the interest in not knowing, I find the solution in spatial privacy and I leave the reader to judge the merits of that concept for him/herself.

Finally, I find myself once again in agreement with Dr Canellopoulou Bottis. We are not poles apart in the end points which we support. While my colleague argues for 'beneficence' in her article – to which she attributes the meaning 'do no harm' – I would suggest rather that we are both concerned with 'non-maleficence': avoiding harm in dealing with patients and their relatives. However, the divergent means that we each advocate to achieve this end will undoubtedly remain the subject of much debate in the years to come[15].

Notes

1. Laurie, G.T.; 'In Defence of Ignorance: Genetic Information and the Right Not to Know', 6, *European Journal of Health Law*, 119, 1999.
2. Thomson, J.; 'Delictual Liability', Second Edition, Butterworths, 1999, chapter 4.
3. *Tarasoff v The Regents of the University of California* 17 Cal. 3d 425; 551 P.2d 334 (1976).
4. The therapist was not required to warn the third party in danger or her parents in order to discharge his duty of care. He could have had the patient committed, without

informing the third parties of any danger, and this would have discharged the duty in question.

5. For further discussion see Laurie, G.T.; 'Obligations Arising from Genetic Information: Negligence and the Protection of Familial Interests', 11, *Child and Family Law Quarterly*, 109, 1999.
6. 87 NJ 53 (1981) at 63-64.
7. 291 N.J. Super. 619.
8. Ibid, at 626.
9. 211 A.D.2d 353 (1995).
10. Ibid at 355-356.
11. Andrews, L.; 'Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks', 29, *Houston Law Review*, 149, 1992 at 181 opines, with good reason, that the recognition of a duty of disclosure to relatives with whom a physician has no direct professional relationship should, logically, also give rise to a duty for physicians to tell strangers of the health risks that they run.
12. See further, Laurie, supra, note 5.
13. For more detailed discussion see, Laurie, G.T.; 'Challenging Medico-legal Norms: The Role of Autonomy, Confidentiality and Privacy in Protecting Individual and Familial Group Rights in Genetic Information', *Journal of Legal Medicine*, forthcoming 2000.
14. This is so absent express statutory regulations such as those that require notification of certain contagious and infectious diseases.
15. Thanks are due, once again, to Professor Kenyon Mason of the Faculty of Law, University of Edinburgh. His comments on my work are always most welcome. However, and as usual, I assume full responsibility for the content of this article.